GOVERNMENT OF INDIA
HEALTH AND FAMILY WELFARE
LOK SABHA

UNSTARRED QUESTION NO:2269
ANSWERED ON:28.07.2017
Free Treatment for rare Genetic Diseases
Fatepara Shri Devajibhai Govindbhai

Will the Minister of HEALTH AND FAMILY WELFARE be pleased to state:

Will the Minister of HEALTH AND FAMILY WELFARE be pleased to state:

(a) whether the Government proposes to provide free treatment for 700 rare genetic ailments;

(b) if so, the details thereof;

(c) whether the Government has made any corpus fund for the said purpose and if so, the details thereof;

(d) whether the expenses for the above said ailments are likely to be shared by the Centre and State Governments; and

(e) if so, the details thereof and the percentage of funds likely to be shared by Centre and State Governments separately?

Answer

ANSWER
THE MINISTER OF STATE IN THE MINISTRY OF HEALTH AND
FAMILY WELFARE
(SMT. ANUPRIYA PATEL)
(a) & (b): The Ministry of Health and Family Welfare has formulated a National Policy for treatment of Rare Diseases in India to progressively build India's capacity to respond comprehensively to rare diseases covering areas of: prevention, awareness generation, training of doctors, funding support for treatment on the parameters to be defined by a Central Technical cum Administrative Committee, promotion of research and development for drugs for treatment of rare diseases and diagnostics at affordable prices and measures for making the drugs for rare diseases more affordable, strengthening of laboratory networks, development of Centres of Excellence etc. On the whole, the Policy seeks to strike a balance between the interest of patients of Rare Diseases and health system sustainability. The Policy also recognises and delineates the role of various Ministries and departments in the area of Rare Diseases.
(c) to (e): Funding mechanism as given in the National Policy for treatment of Rare Diseases in India is as under:
â€¢ Setting up a corpus fund at Central level with the initial amount of Rs. 100 crore towards funding treatment of rare genetic diseases.
â€¢ Similar corpus at State level and contribution of funds by the Centre towards the state corpus to the ratio of 60:40 out of the central pool.
â€¢ It is up to the States to have a corpus of a larger amount. Requirement of funds by States is as per PIP process.